

DATA DEVELOPMENT SUBCOMMITTEE DRAFT MINUTES
April 30, 2019 – 4:00 PM
Margaret M. O'Neill Bldg. 2nd Floor Conference Room, Dover, DE

QUORUM MET – 4 OF 7

PRESENT: Karen **McGloughlin**, **CHAIR**, Director of Women's Health,; Christine **Applegate**, EN Navigator, Bayhealth; Andrew **Buridan**, Brain Injury Advocate/Support Group; Nicholas **Duko**, Program Manager, LTSS, BCBS Highmark Health Options; John **McNeal**, Director SCPD and Dee **Rivard**, SCPD Support.

ABSENT: Thomas **Cairo**, Bayhealth Neurosurgery; Ann **Phillips**, Parent of a survivor; Brian **Eng**, Esquire, Community Legal Aid Society, Inc., Disabilities Law Program;

GUESTS: (Not able to vote or count toward quorum)

IN-PERSON – Randall J. Farmer, COO and Terri Lynn Palmer, Director of Data Analytics, Delaware Health Information Network (DHIN); DHIN website: <https://dhin.org/>

TELECONFERENCE PARTICIPANTS: None

CALL TO ORDER

Karen called the meeting to order at 4:10 p.m., thanking Mr. Farmer and Ms. Palmer from Delaware Health Information Network for attending today's meeting. Karen requested that everyone around the table introduce themselves.

NEW BUSINESS – DHIN Specification Discussion

Karen told everyone that today's meeting relates to the progress the Data Development Subcommittee (DDS) made on the draft specifications for our data request from DHIN. Nick put together a simple spreadsheet that the subcommittee shared with the larger Brain Injury Committee (BIC) to request input prior to their finalization of today's meeting with DHIN.

- Randy Farmer advised that if the information is available from DHIN that they will want the BIC/DDS to pull a minimum of a one year look-back.
- Terri Lynn went a step further advising that of the 22 items requested on the BIC/DDS specification list, there are only 7 that are not currently part of their data stream.
- Randy, by way of providing background information, advised that DHIN is restricted by their agreements with the hospitals for the data they receive. There are five conditions that DHIN must consider and they are: payment, treatment, operations, compliance with

the law, and patient consent. There is one exception; though, where even if we had patient consent DHIN could not share the data. However, if we need to understand the incidences of head trauma by county, DHIN is able to do that because they are sharing meta-data. Randy inquired as to what degree we need a unique patient identifier.

- Karen advised that we are going to look at this project in phases. For the first phase we need an accurate recording of the total number of TBIs in the state.
 - Can DHIN accomplish this with an assigned account number?
 - The BIC/DDS wants to know the higher level numbers and would really like to know the time lag between when a TBI is sustained and when the patient is seen.
 - Does DHIN have data on the last relatable time that the TBI patient was seen?A brain injury can last months and sometimes forever. Unfortunately, we don't know that TBI survivors are being taken care of throughout their extended need for services.
- Terri Lynn and her team will have to do some digging for the time between occurrence and time seen. However, if a TBI is sustained from an auto injury, there is a requirement to report it.
- Karen advised that of all of the different categories of causes of a brain injury it is important to know specifically what caused the injury for tracking purposes in Delaware. The BIC/DDS is looking to identify the state agencies and non-profits that are treating and offering services to those specific types of injuries. For instance, we have the "Z" type injury or whatever it may be and for some reason it is suddenly occurring more consistently. This would require research to find out why it is occurring, where it is most prevalent, and the reason for the increased frequency in order to provide prevention, education, placement of services and outreach.
 - Andrew confirmed that once BIC/DDS gains access to data from specific categories that we would still be able to request additional data assuming that the data being requested is being reported.
 - Karen stated that it is useful to break the data down by sex, age and race.
- Terri Lynn advised that DHIN's goal is to get the data to us as soon as possible. The claims data de-identifies under the DPH nametag. Since the BIC/DDS is not a state entity that falls under DPH they have to verify our authorization for extraction of the data.

- John advised that the State Council for Persons with Disabilities (SCPD) is the clearinghouse for all individuals with disabilities. Karen informed the group that the BIC would have to work toward developing regulations on how we will handle the data?
- Randy advised that DHIN currently has interagency agreements with SEBC, DPH, DMMA, and OMB. Unfortunately, the BIC is not under any of those agencies and may need an interagency agreement. If DPH is the governing body for the claims database, we might not be able to obtain the information. If it is the state that is requesting the data especially if it is de-identified data it might be covered under the interagency agreement. This data gives us the broad strokes but does not provide the Injury Severity Scale (ISS). DHIN will pull all of the data being requested. He suggested that the BIC/DDS start with 13 months instead of a year. Terri Lynn suggested making our request data rich by requesting 2 years instead of just 1 year. Ideally she suggested requesting 25 months of data, which would include the data from the starting month the previous year. All data would come with a blind identifier in order to follow an individual's treatment throughout the 2 year time period. However, race is not a requirement in their claims database. The first data pass could include claims along with all of the other associated diagnosis and descriptive terminology associated with brain injuries. The data would be identified no matter where it falls in the diagnosis level. DHIN will have to make sure that they pull this information for us. DHIN receives 1 primary diagnosis with up to 12 secondary diagnoses. Data for 2 years includes the primary diagnosis level along with the 12 different diagnoses levels. DHIN is able to get the data for those individuals blinded and limited to the claims data. This would be "Phase 1" of the BIC/DDS project.
- Questions included: How is additional information obtained at a later date? What tools are used to manipulate the data? What about age groups or counties?
- At the last meeting we talked about DHIN possibly providing some sort of a web portal that would enable the BIC/DDS to manipulate the data with queries instead of within Excel. Mr. Farmer stated that it is DHIN's intent in cases like this where a state agency is using the data to explore and is not looking specifically for one specific report to establish a website portal with the extracted data behind it. There is no reason why the BIC/DDS couldn't be the first ones to test the portal. DHIN would pull the extracted data using the interface "Tableau" which is very easy to use. Terri Lynn's team is available for

consultation; however, at this time, DHIN does not know what additional charges they may incur with the portal yet that. This prevents them from providing a price for the portal usage until it is fully operational.

- Randy will look into what DHIN is allowed to do first. He stated that the July 2016 agreement signed by former Governor Markell stipulated 4 specific agencies that have unfettered access to the data. (OMB, SEBC, DMMA, and DPH)
- Karen advised that the BIC is not averse to asking the Governor to include Homeland Security or more specifically SCPD as one of the agencies included by the agreement.
- John shared that the SCPD and the BIC are statutorily required to be the clearinghouse for all disability and brain injury data for the state. The SCPD has tried to obtain data for such a long time. John believes that we need a DHIN type of system for employment data and a DHIN type of system for disabilities data.
- Randy feels that DHIN is going to find a way to yes. He stated that restrictions on the clinical data do not apply because by virtue of law, the DHIN is compelled to share the data for the good of all.
- John advised that the Department of Safety & Homeland Security (DSHS) is very good with providing any information and support that SCPD needs. Randy advised that the DHIN data is not subject to subpoena; however, there are regulations that cover access to the data.
- Karen advised that the other side of this issue, is what the BIC/DDS does with the data and we will need to put it in writing by creating a policy and regulations. The DPH has a medical board that reviews the privacy of any data they receive and handle. How will the BIC/DDS handle the publication of any data that we need to publish? The DHIN will have guiding documents that will need to be executed and they are happy to help us do our due diligence.
- Terri Lynn advised that we have the hurdles of what sanction our request fall under and whether or not we need an interagency agreement. Additionally, we need to consider whether or not we need to change Title 16 in order to provide the data. DHIN staff will find out the best path forward for both data sets for 25 months of data in order to enable us to explore. DHIN will have to determine where to find the information in their data as well as the location of services received and the country of the survivor.

- Karen believes that because Delaware is such a small state there may be insufficient data for individual specific occurrences; however, the BIC/DDS still wants to receive the data to follow in order to track that traumatic brain injury (TBI) survivors are receiving the appropriate care. She assured everyone that this is not an audit of medical facilities at all. She asked if there is a way to ensure that the BIC/DDS receives the data even if it returns only 2 instances of a specific level of TBI so that we can review it in an exploratory way.
- Terri Lynn responded that there is a way for DHIN to accomplish this request. Terri Lynn advised that right now DHIN is limited in their claims data with Medicaid, Medicare, and State Payers. However, DHIN is adding commercial data as they move forward and are currently loading AETNA data into their system. The DHIN is able to follow TBI occurrences through care providers because they assign unique identifiers to the data for places of service in DE and MD. Once the clinical data is included, it will provide a full picture. However, if someone in Kent County sustains a TBI and has to go to Bryn Mawr for treatment then we lose data because Bryn Mawr does not report data to DHIN. This results in the data having some gaps. The claims data is mostly complete if the patient is a Delaware resident. The full picture involves clinical and claims data together. Once the BIC/DDS request includes the claims data, we will be able to see patterns and continue to refine our data request.
- John wanted to ensure that we are talking about traumatic brain injuries and not acquired brain injuries (ABI) because the Brain Injury Committee and SCPD are constantly having conversations about expanding the TBI Fund to include limited acquired brain injuries.
- Karen assured him that the DDS decided early on to tackle one phase of this project at a time. Once we are able to receive TBI data and analyze it in Phase I; then we can go back and decide to change our request in order to include ABIs as part of Phase II. The DDS already has all of the groundwork completed. Once the DHIN obtains the ICD-10 coding for other specific ABIs it can easily include that data into our original request.
- Randy Farmer stated that DHIN's ability to share data is predicated on keeping requests to a single purpose which enables them to walk the request through their system in order to obtain approval.

- Randy believes that DHIN can cover both with ICD-10 codes and other types of nomenclature specific to TBI occurrences. This adds to the efficiency of being able to leverage this type of information. DHIN already received the ICD-10 Code listing for TBIs from the BIC/DDS. He believes that what we have here is not a technology problem. However, the DHIN needs to confirm that the legal side is not a problem, and then confirm that data availability is not a problem.
- Terri Lynn advised that the website portal isn't actually active yet. Presumably by the time DHIN gets the legalities figured out, the portal may be in place; however, the timing is unknown at this point.
- Karen advised that if we run into roadblocks, we can go that way at a later date as a Plan B; however, for now the BIC/DDS would prefer to keep all of the data together.
- Randy advised that Governor's Carney's Office and the University of Delaware, Medical Research Department are helping DHIN officially celebrate the unveiling of the DHIN portal tomorrow.
- Karen stated that the evolution of technology has happened so fast.
- The BIC/DDS and DHIN representatives discussed the timeline for working through the legal aspects with Karen advising that the BIC/DDS will need to know sooner rather than later, if we will need to introduce legislation in order to obtain access to the data before the end of this Legislative session.
- Randy advised that the DHIN should be able to tell us within 3 weeks. DHIN will work with their team to have their data available within a 3 month time period.
- Karen advised that there is a great deal that the BIC/DDS can do that involves focus and planning. The significant piece of this project will focus on where we need to allocate resources throughout the state. Another piece includes working on the educational aspect in order to advocate for prevention of TBIs through changed habits such as wearing helmets, seatbelts, and ensuring the reporting of every concussion to a medical provider.
- John shared that the BIC is also statutorily mandated to do provide an annual report to the Legislature. In answer to the question of how many TBIs are occurring per year, John responded that it depends on your definition. With a more significant TBI, the best tracking component is Medicaid because they are the ones paying for care.

Concussions typically result from falls, car accidents, and sports injuries. The Department of Education (DOE) has data within the educational setting; however, it depends on the level. We also have the Delaware Concussion Protection in Youth Athletic Activities Act (CPYAAA) for non-scholastic activities which identifies another way to track brain injuries.

- The DHIN claims data is able to see claims from radiology reports. So if someone in Delaware sustains a concussion and never goes to see a doctor but they got an x-ray, DHIN is able to see the radiology report. Terri Lynn stated that we should also include information on what the financial impact is to the State of Delaware.
- Karen and John advised that there are articles published on the cost of brain injuries. It is important to answer what the cost to Medicaid is in terms of TBI injuries? The Trauma Registry publishes brain injury data. However, the information that will matter the most is the financial cost to the State of Delaware. She advised also including the number of children affected from sports injuries and then applying lifetime costs for treatment of their moderate to severe concussions which are brain injuries.
- The next time we meet, we will have a legal discussion with big numbers.
- Randy Farmer shared that requests such as ours really gets the DHIN's juices flowing in terms of the applicability of what they can help with.
- Andrew volunteered to bring donuts to the next meeting.

NEXT STEPS

- DHIN will work on the legal aspects of our request with their attorney and present our request to their Board.
- DHIN will determine what sanction our request falls under and whether or not SCPD will need an interagency agreement.
- The DDS needs to send Randy simple statements of the top 10 things that the BIC/DDS plans to do with the data once they receive it.
- Do we need to change Title 16 in order to have the DHIN provide the BIC/DDS with data?
- The DHIN's ability to share data is predicated on keeping requests to a single purpose and walking it through their system in order to obtain approval.

- The BIC/DDS needs to send Randy and Terri Lynn a list of keywords to search for in the data that will include words and phrases such as: head trauma, concussion, penetrating head injury, brain injury, etc., that we will want included as part of the DHIN's data queries.
- Answer what the financial cost is to Medicaid for TBI injuries.
- What is the cost to the State of Delaware for TBI cases?
- Setup a tentative meeting for 3 weeks out.
- Develop regulations on how the SCPD/BIC and the DDS will handle the data it receives.

ADJOURNMENT

- Andrew made a motion to adjourn that Nicholas Duko seconded. Karen called for discussion and hearing none, voting subcommittee members present unanimously approved the motion to adjourn.
- With no further business to discuss the meeting adjourned at 5:15 p.m.

NEXT MEETING – Is tentatively set for **Tuesday, May 28 from 4:00 – 5:00 p.m.**, pending notice from DHIN that legalities were resolved.